



Section 9:

References and Resources

Contents of Section 9

Requesting Materials from HRSA's HIV/AIDS Bureau (HAB)

HAB Publications about PLWH Involvement in CARE Act Programs

HRSA HIV/AIDS Bureau Cooperative Agreements

CARE Act Materials Available in Spanish

Selected Reports and Periodicals from Non-HAB Sources

Other Resources



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act



Requesting Materials from HRSA's HIV/AIDS Bureau (HAB)

Following is an annotated bibliography of PLWH-related materials. It includes a group of materials prepared for what is now the HIV/AIDS Bureau (HAB), Health Resources and Services Administration (HRSA). Also included are selected PLWH-related materials from non-HAB sources, both within and outside the Federal government. Included are reports of studies about PLWH involvement in CARE Act programs, summaries of discussion group meetings involving PLWH and HAB personnel, a report from a technical assistance conference call, reports summarizing the content of PLWH workshops held at national Title I and Title II meetings, training guides, PLWH newsletters, and other documents which do not focus entirely on PLWH but include PLWH-related information. Some of these materials were prepared by HRSA's HIV/AIDS Bureau under its Technical Assistance Contract (TAC).

The HRSA/HAB documents referenced can be obtained using the HRSA/HAB website at: <http://www.hrsa.gov/hab/> or by calling the HRSA Information Center at 1-888-ASK-HRSA.

In addition, you can contact the following HAB offices for additional information.

Titles I, II and ADAP

Division of Service Systems
HIV/AIDS Bureau, HRSA
5600 Fishers Lane, Room 7A-55
Rockville, MD 20857
Telephone: (301) 443-6745
Fax: (301) 443-8143

Title III, Title IV and AIDS Dental Reimbursement

Division of Community Based Programs
HIV/AIDS Bureau
5600 Fishers Lane, Room 7-74
Rockville, MD 20857
Telephone: (301) 443-9051
Fax: (301) 443-1728

AIDS Education and Training Centers (AETCs)

Division of Training and Technical Assistance
HIV/AIDS Bureau, HRSA
5600 Fishers Lane, Room 9A-39
Rockville, MD 20857
Telephone: (301) 443-6364
Fax: (301) 443-9887



Special Projects of National Significance (SPNS)

Office of Science & Epidemiology
HIV/AIDS Bureau, HRSA
5600 Fishers Lane, Room 7A-08
Telephone: (301) 443-9976
Fax: (301) 443-4965

CARE Act Program Evaluation

Office of Science & Epidemiology
HIV/AIDS Bureau, HRSA
5600 Fishers Lane, Room 7A-07
Rockville, MD 20857
(301) 443-6560
Fax: (301) 594-2511

HAB Publications about PLWH Involvement in CARE Act Programs

HAB Reports and Periodicals

HRSA Care ACTION: Providing HIV/AIDS Care in a Changing Environment. Published by the Health Resources and Services Administration, Washington, D.C. (about 12 pages); available free.

- **Focus:** Serves as a newsletter for the HIV/AIDS Bureau, providing information related to the implementation of the Ryan White CARE Act.
- **Content:** Covers legislative status of the Act, specific programs and issues, policies and guidances, new reports, upcoming meetings and events, and other information of broad interest to grantees, planning bodies, providers, PLWH, and others concerned about HIV/AIDS services.

Report of the Fifth Annual Community Discussion Group Meeting, June 9-11, 1997, Washington, D.C. Prepared by what is now the HIV/AIDS Bureau, July 1997. Two forms of the report are available: full report (34 pages) and executive summary (3 pages). Executive summary is included in this document (see Section 10).

- **Focus:** Report of the fifth community discussion group meeting convened by what is now the Division of Service Systems, HIV/AIDS Bureau. The meeting included one day of joint meetings and a day and a half of separate sessions for Title I and Title II representatives, and represented HRSA's most comprehensive dialogue with consumers regarding the planning, implementation, and oversight of Title I and Title II. Participants included 28 people living with HIV disease from Title I planning councils and Title II consortia throughout the nation, as well as numerous HRSA staff. The group was ethnically diverse, and about 40 percent were women; the large majority had not attended a previous community discussion group.



- **Content:** Report summarizes discussion and participant recommendations on a variety of topics. It also summarizes HRSA updates, specialist presentations, and participant viewpoints on the following topics of interest to both titles: confidentiality and disclosure of HIV status, ADAP, working with national AIDS organizations, allowable services under Title I and Title II, training materials, and technical assistance opportunities, services for substance abusers, issues in managed care and case management, and a process for developing a PLWH caucus. The report also covers discussions with Title I PLWH representatives on grievance procedures and the open nominations process, two new requirements under the CARE Act Amendments of 1995; and discussions with Title II representatives on legislative changes related to Title II and the role of advocacy in Title II programs.

Report of the Fourth Annual Community Discussion Group Meeting, September 11-13, 1996, Washington, D.C. Prepared by HRSA's HIV/AIDS Bureau under the Technical Assistance Contract, with final revisions in February 1997. Two forms of the report are available: full report (36 pages) and executive summary (6 pages).

- **Focus:** Report of the fourth community discussion group meeting convened to consult with people living with HIV disease who are members of CARE Act planning bodies. Attending were 30 PLWH from Title I planning councils and Title II consortia; about 60 percent were people of color and 40 percent were women. This was the first community discussion group to include not only joint sessions, but also separate sessions for Title I and Title II representatives.
- **Content:** Report summarizes discussion and recommendations from PLWH regarding a variety of topics related to effective PLWH participation and to CARE Act services. Among the topics addressed in depth are the implications of recent medical advances for CARE Act programs, issues related to ADAP, the policy development process, the importance of improving communications with PLWH and PLWH groups, approaches for attaining and maintaining effective PLWH participation in planning bodies, and special issues related to minority PLWH participation. Service-focused topics include outreach and access to services, case management, and services to substance abusers.

Report on the Third Community Discussion Group Meeting with People Living with HIV Disease. Report of a meeting held October 17-19, 1995, Washington, D.C. Prepared by what is now the HIV/AIDS Bureau under the Technical Assistance Contract, October 1995. Two forms of the report are available: summary report (16 pages) and executive summary (2 pages).

- **Focus:** Report of the third community discussion group meeting convened to provide a dialogue among PLWH and between PLWH and HRSA, with special focus on the involvement of PLWH in implementation of the CARE Act. Participants included 22 PLWH from throughout the country, half of them people of color and eight of them women, as well as many HRSA representatives.
- **Content:** Report summarizes a range of issues related to PLWH involvement in CARE Act implementation which were addressed at the meeting. Includes extensive discussion of obstacles to effective PLWH involvement on planning councils and consortia and how to overcome them. Also addresses issues raised by grantees regarding PLWH roles and involvement, concerns about provider conflict of interest, and service implications of the fact that PLWH now may live a long time and at times not require intensive services. Discusses the need for HRSA guidance, orientation, training, and other initiatives designed to improve communication and mutual respect between PLWH and other planning body members.



Summary Report: *Second Community Discussion Group Meeting—Implementation of the Ryan White CARE Act and Technical Assistance Plan.* Summary of a meeting held October 30-31, 1994, in Washington, D.C. Draft report prepared by what is now the HIV/AIDS Bureau; revised version prepared April 1996.

- **Focus:** Report of the second community discussion group meeting convened by HRSA. Participants included 12 PLWH, half of whom had attended the first community discussion group meeting in 1993. Major tasks included review and discussion of a proposed HRSA policy on PLWH participation in Title I, identification of additional strategies that can be used by DSS to encourage and support effective PLWH participation, and discussion of channels for continuing dialogue between HRSA and the PLWH community.
- **Content:** Report organized by topic, with each topic typically including quotations from PLWH, background information as needed, recommendations, and a summary of the discussion. Topics include an update on recommendations from the 1993 meeting; the findings of the study on The Participation of People with HIV in Title I HIV Health Services Planning Councils (See reference in this bibliography); information, skills, and other assistance needed for effective PLWH participation in CARE Act governance; CARE Act reauthorization; and the improvement of communications among HRSA, CARE Act planning bodies, and the PLWH community.

Summary Report: *Persons Living with AIDS Community Discussion Group Meeting. Summary of a meeting held July 19-20, 1993, in Washington, D.C.* Published together with reports from three other meetings with CARE Act constituencies (13 pages).

- **Focus:** Report of the first community discussion group meeting convened by what is now the Division of Service Systems, HIV/AIDS Bureau. Purposes were to obtain PLWH views of the problems which exist in operating CARE Act programs, as well as recommendations for administrative and program policies and for consideration in the reauthorization of the CARE Act.
- **Content:** Discussion covered five broad topics: planning council/consortium composition, needs assessment, the planning process and program implementation, funding, and evaluation. Report is organized by topic and, within topics, by issue area, including a statement of the issue, a brief summary of the discussion including quotations from PLWH participants, and a list of possible solutions/options.

Final Report: *The Participation of People with HIV in Title I HIV Health Services Planning Councils.* Prepared by HRSA, HIV/AIDS Bureau, September 1994 (72 pages plus six appendices).

- **Focus:** A research report summarizing results of a six-month study of the participation of people with HIV in Ryan White CARE Act planning councils. Based on in-depth interviews and focus group discussions with 113 individuals—90 of them HIV-positive—in four Title I cities: Atlanta, Philadelphia, San Diego, and Seattle. Recommendations are directed at planning councils. Includes many lists and summary points.
- **Content:** Includes three major sections, each providing an analysis and discussion of major issues and ending with a set of recommendations: (1) recruitment of HIV-positive individuals to become planning council members; (2) the representation of HIV-positive members, from planning council and member perspectives; and (3) methods of participation of HIV-positive individuals as members and non-members.



How to Secure and Maintain PLWH Participation on Planning Councils and Consortia: Putting the Pieces Together. Report of a workshop held June 28-29, 1995, at the National Title I and Title II Grantee Meeting, Washington, D.C. Prepared by what is now the HIV/AIDS Bureau under the Technical Assistance Contract, August 1995 (10 pages).

- **Focus:** Content summary of a workshop held on two afternoons as part of the 1995 national meeting of Title I and Title II grantees. Designed to help grantees understand the importance of including PLWH in CARE Act activities, and develop a strategic planning approach to recruiting, orienting, and maintaining PLWH in CARE Act activities. Lead facilitator was Bill Lottero, Director, Consumer Advisory Board (CAB) System, Massachusetts Department of Public Health, HIV/AIDS Bureau, Boston.
- **Content:** Summarizes presentations and discussion including about 40 participants during two half-day sessions. Identifies many benefits of PLWH involvement in Ryan White CARE Act activities. Emphasizes the need for grantees to be clear about their “full intention” and real goals regarding PLWH involvement, and describes the kinds of commitment needed as a foundation for successful recruitment and retention of PLWH. Includes discussion of common obstacles to effective PLWH involvement in CARE Act activities and ways to overcome them.

The Involvement of Persons with HIV/AIDS in Title I and II Programs. Report of a technical assistance conference call held December 14, 1994. Prepared by what is now the HIV/AIDS Bureau under the Technical Assistance Contract, August 1995 (13 pages).

- **Focus:** Summary of a technical assistance conference call designed to discuss requirements for and success in involving persons living with HIV/AIDS (PLWH) in CARE Act Title I and Title II programs. Discussion focused on topics covered in two specific documents: (1) Policy #1 on Participation of People with HIV Disease on Title I HIV Health Services Planning Councils; and (2) the report, Participation of People with HIV/AIDS in Title I HIV Health Services Planning Councils.
- **Content:** Describes the importance of effective PLWH involvement and the challenges of accomplishing it. Describes Policy #1, which applies to planning councils, and HRSA expectations for a similar level of PLWH participation in Title II consortia. Summarizes the findings of the report on PLWH participation, including factors that encourage or discourage the recruitment and sustained participation of PLWH on planning councils, and ways to obtain input from and provide feedback to PLWH who are not planning council members. Conference call also included broad discussion of issues and HRSA initiatives related to ensuring full inclusion of PLWH in CARE Act programs. Also describes HRSA, State, and EMA activities designed to facilitate PLWH involvement in Title I and II activities.

Participation of People Living with HIV in State HIV Care Planning and Programs: A Review of State Activities under Title II of the Ryan White CARE Act. Prepared for what is now the HIV/AIDS Bureau, July 1998.

- **Focus:** An assessment to determine patterns of PLWH participation in CARE Act Title II State and consortium-level activities, including levels of participation and barriers to effective and meaningful participation, and make recommendations to DSS on how to promote PLWH participation in Title II programs in the future.



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act

- **Content:** Includes information obtained through a written survey sent to all State AIDS Directors and Title II program directors, a written survey of members of the ad hoc PLWH advisory group to what was then the Division of Service Systems, and descriptions of successful models of participation at the State and consortium levels. Sections address the purpose of PLWH participation in Title II activities, ways in which PLWH participate, participation in Statewide advisory groups, participation in ADAP advisory groups, other Statewide non-consortium activities, participation in consortium activities, technical assistance needs of State Title II programs, and a summary of key findings and recommendations.

Social and Structural Barriers to HIV/AIDS Care as Identified by Ryan White CARE Act Title I Grantees, FY 1993. Prepared for HRSA, HIV/AIDS Bureau, March 1996 (19 pages).

- **Focus:** Summary of barriers to HIV/AIDS services and activities taken to overcome them, as reported by Title I grantees as part of their FY 1993 Supplemental Grant Applications. Report represents the first systematic report from Title I grantees about barriers to care. Application presented nine possible barriers in table format, and asked grantees to indicate which barriers applied to their EMA, identify any other barriers, and describe activities undertaken to address these barriers.
- **Content:** Identified barriers included lack of awareness of services, lack of services which directly enhance access (*e.g.*, transportation, child care), lack of emerging/grassroots provider experience to (1) meet administrative requirements and (2) develop competitive proposals, lack of personnel/provider language or cultural competency, lack of primary provider knowledge about caring for PLWH, lack of "traditional" service provider experience in serving people of color/others, and lack of ethnic/community provider experience in serving gay men with HIV/AIDS. Report includes a wide range of activities undertaken by EMAs to overcome or minimize these barriers.

HAB Manuals, Pamphlets and Self-Assessment Modules

Training Guide: A Resource for Orienting and Training Planning Council and Consortium Members. Prepared by what is now the HIV/AIDS Bureau under the Technical Assistance Contract. Published in March 1997.

- **Focus:** A training guide designed to assist Title I and Title II programs in ensuring that all planning body members have the information and skills for full participation in CARE Act planning and implementation activities. Special emphasis on PLWH recruitment, effective involvement, and retention as planning council and consortium members.
- **Content:** Includes four sections. Chapters 1 and 2 provide introductory materials designed to familiarize users with the content, purposes, and organization of the Training Guide. Chapter 3 includes three content areas and seven training modules: (1) Membership and Participation: PLWH Recruitment; Member Involvement and Retention; (2) What Every Planning Council and Consortium Member Should Know: Implementation of the Ryan White CARE Act; Grantee, Planning Council, and Consortium Roles and Responsibilities; Planning Council and Consortium Structure and Governance; and (3) Working Together Effectively: Group Process and Decision Making; Interactive Skills and Challenges. Chapter 4, Training Techniques and Aids, provides information and materials designed to help less-experienced presenters prepare to deliver effective orientation and training. Appendices provide supplementary information including a glossary of terms and a set of reference materials and resources.

People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act



Planning Council Primer. Prepared by the HIV/AIDS Bureau under the Technical Assistance Contract Published in 1997. (24 pages).

- **Focus:** The Planning Council Primer provides a summary of the roles and responsibilities for planning council members and other partners in the Title I planning process. Written in clear and non-technical language, it is designed for use by individual planning council members.
- **Content:** This pamphlet contains all the basic information needed by every planning council member. Includes a short overview of the CARE Act and Titles, eligible services under Title I, planning council and grantee responsibilities, and shared responsibilities. Describes Title I roles and responsibilities, typical structure and bylaws of a planning council, and availability of technical assistance. Available in English and Spanish.

Self-Assessment Modules. Modules include Comprehensive HIV Services Planning, Continuum of Care, Developing and Pursuing the Mission, Needs Assessment, Priority Setting and Resource Allocation, and Representation and Diversity. Prepared by what is now the Division of Service Systems, HIV/AIDS Bureau, June 1997.

- **Focus:** Six separate modules designed to help grantees, planning councils, and consortia assess their effectiveness and develop action plans to strengthen their performance in critical areas of responsibility defined by the Ryan White CARE Act. Modules were pilot-tested with Title I and Title II planning bodies and revised based on their input. Available to grantees and planning bodies for their use, which is voluntary. Each planning body is free to determine which area(s) it wants to assess, when to conduct the self-assessment, the scope of the assessment, and with whom they will share results.
- **Content:** Each module includes appropriate definitions, and addresses key questions about conducting the self-assessment, including: Who should use this module? Who conducts the self-assessment? What activities should be part of the self-assessment? How much time and money are required? A suggested timeline for the self-assessment is also provided, and types of information needed to complete each specific module are identified. Each module then includes a series of self-assessment questions, with suggested scoring and discussion of the scoring, and a process for identifying strengths and weaknesses and developing action steps to strengthen performance. At the end of each module are references, including a list of legislation, HRSA documents, articles, and books related to the topic. Also included are policy and reference documents and other supporting materials related to the topic, such as suggested benchmarks to use in the self-assessment process. Modules are designed to be used either independently or as a full series; information is complementary and modules are cross-referenced. Representation and Diversity module includes most extensive direct references to PLWH involvement in planning bodies.



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act

Title I Manual. Prepared by what is now the Division of Service Systems, HIV/AIDS Bureau under the Ryan White CARE Act Technical Assistance Contract, March 1997.

- **Focus:** Manual for CARE Act Title I grantees and planning councils as well as anyone else involved in fulfilling Title I requirements. Brings together many documents addressing Title I administration and implementation, including specific materials related to Title I requirements and responsibilities, tools and resources.
- **Content:** Contains six sections: (1) General Information such as an overview of the CARE Act, HRSA fact sheets, and a glossary of terms; (2) Grant Administration, including information useful in the local administration of Title I grants; (3) Reporting, describing grantee reporting responsibilities; (4) Policies and Program Guidances, including legislative requirements and DSS expectations; (5) Technical Assistance Papers providing instruction on how to conduct many of the activities undertaken by grantees, planning councils, and PLWH caucuses; and (6) CARE Act Contacts, including EMA contacts, a PLWH Directory, and a DSS Project Officer assignment list. Organized in looseleaf format with section title pages for easy copying and stand-alone use.

Title II Manual. Prepared by the HIV/AIDS Bureau's Division of Service Systems under the Ryan White CARE Act Technical Assistance Contract, February 1999.

- **Focus:** Manual designed for Title II grantees, consortia, and lead agencies, and for others involved in CARE Act Title II planning and implementation. Brings together many documents addressing Title II administration and implementation, including specific materials related to Title II requirements and responsibilities. Clarifies roles, responsibilities, and HAB expectations for grantees, consortia and Statewide advisory groups, lead agencies, and the affected community.
- **Content:** Contains six sections: (1) General Information including CARE Act legislation, HIV/AIDS Bureau structure, Title II contacts, and a glossary of terms; (2) Grants Administration, addressing program and fiscal monitoring, grants management, preparation of effective applications, and budgeting and financial issues; (3) Reporting, describing grantee narrative and budget reporting responsibilities and the Annual Administrative Report; (4) Policies and Program Guidances, including legislative requirements and HAB expectations for program planning and implementation and for shared responsibilities such as the Statewide Coordinated Statement of Need; (5) Technical Assistance Papers providing instruction on many Title II responsibilities and activities, from consortium structures to priority setting and evaluation, as well as issues such as managed care and meeting service needs in very rural areas; and (6) a Developmental Manual for Title II Consortia, addressing consortium responsibilities, structures, and processes. Organized in looseleaf format with section title pages and chapter summaries, to clarify content, simplify copying, and encourage stand-alone use of individual chapters.



HRSA/HIV/AIDS Bureau Cooperative Agreements

Cooperative agreements were established in 1998-99 by the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB), with six national HIV/AIDS organizations to develop technical resources and enhance HAB communications with the CARE Act community. HAB goals are for national organizations to: provide HAB with ongoing consultation access; serve as information exchange forums, including broader dissemination of HAB products; produce technical assistance materials; and conduct training.

A description of the cooperative agreements is below, followed by a listing of selected accomplishments. Many of these accomplishments focus on topics directly affecting PLWH, including a booklet to help consumers navigate managed care; trainings and conferences for PLWH; development of computer and Internet resources, presentations and trainings; and other resources.

AIDS Action Foundation

1906 Sunderland Place NW
Washington, DC 20036
Phone: (202) 530-8030
Fax: (202) 530-8031
<http://www.aidsaction.org/>

AIDS Action Foundation represents 3,200 organizations nationwide, including 1,800 of the nation's leading community-based organizations and the people living with HIV they serve. AIDS Action advocates for effective and fair national AIDS policies, and conducts research and education initiatives to enhance care and services for people living with and affected by HIV.

AIDS Action's cooperative agreement with HAB develops technical assistance materials to assist community based organizations (CBOs) in (1) developing and implementing adherence programs, especially those targeted to hard-to-reach populations and (2) understanding and adapting to Medicaid managed care and other changes in the financing of HIV care. AIDS Action also provides information to HAB on current issues and challenges facing community based organizations (CBOs). AIDS Action addresses these issues through policy analysis, training and technical assistance, materials development and dissemination, and the production of policy briefs on key issues related to HIV.

AIDS Alliance for Children, Youth, and Families

Formerly, AIDS Policy Center for Children, Youth, and Families
1600 K Street, NW, Suite 300
Washington, D.C. 20006
Phone: (202) 785-3564
Fax: (202) 785-3579
<http://www.aidspolicycenter.org>



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act

AIDS Alliance for Children Youth and Families was founded to respond to the unique concerns of HIV-positive and at-risk children, youth, women, and families. AIDS Alliance conducts policy research, education, and advocacy on a broad range of HIV/AIDS prevention, care, and research issues. Organizational members include 500 community-based agencies in 27 states, the District of Columbia, and Puerto Rico. Individual members include young people, women, and family members throughout the United States. Many of AIDS Policy Center's members provide or receive services funded by Title IV of the Ryan White CARE Act.

AIDS Alliance's HAB cooperative agreement develops products and training materials addressing traditionally under-served populations living with HIV/AIDS, with an emphasis on all-CARE Act Title program usability.

National Alliance of State and Territorial AIDS Directors

444 N. Capitol Street, N.W., Suite 339
Washington, DC 20009
Phone: (202) 434-8090
Fax: (202) 434-8092
<http://www.nastad.org/>

Founded in 1992, the National Alliance of State and Territorial AIDS Directors (NASTAD) represents the chief HIV/AIDS program administrators who are responsible for managing federally funded and state-funded HIV/AIDS health care and prevention programs in each state and territory. State AIDS directors administer federally funded HIV prevention and surveillance activities and coordinate the administration of the Federal Ryan White CARE Act Title II programs that organize systems of health care for low-income individuals with HIV disease in every state.

NASTAD's cooperative agreement with HAB includes: (1) development of six monographs on best practices of state HIV care programs; (2) participation in the Data and Evaluation Work Group to provide policy input provided to HRSA on long-term data and evaluation issues; and (3) preparation of a report summarizing findings from a 1999 survey of state AIDS directors on state HIV service activities with state mental health and substance abuse programs.

National Association of People with AIDS

1413 K Street, N.W., 7th Floor
Washington, DC 20005-3405
Phone: (202) 898-0414
Fax: (202) 898-0435
<http://www.napwa.org/>

The National Association of People With AIDS (NAPWA) advocates on behalf of all people living with HIV and AIDS in order to end the pandemic and the human suffering caused by HIV/AIDS. NAPWA serves as a national information resource for people living with HIV, their care givers and the general public, as well as an advocacy organization dedicated to bringing forth the issues and concerns of people living with HIV.

NAPWA's cooperative agreement with HAB is designed to facilitate the involvement of persons living with HIV/AIDS (PLWH) in CARE Act planning processes. NAPWA disseminates HIV treatment education information to the CARE Act community (including PLWH and community based



organizations) and to the general public. NAPWA also develops consumer managed care materials, assists with the promotion of National HIV Testing Day, and convenes the annual Ryan White National Youth Conference on HIV and AIDS. NAPWA's technical assistance activities are designed to increase the development of PWA leadership skills, thus guiding them into care and making them more effective participants in community planning processes.

National Minority AIDS Council

1931 13th Street, N.W.
Washington, DC 20009-4432
Phone: (202) 483-6622
Fax: (202) 483-1127
<http://www.nmac.org/>

The National Minority AIDS Council (NMAC) was formed in 1987 to develop leadership within communities of color to address issues of HIV infection. NMAC's goals are to serve as a powerful national voice for front line AIDS workers, provide leadership on HIV/AIDS, and provide comprehensive technical assistance and training.

NMAC's cooperative agreement with HAB provides the following training/technical assistance and capacity building activities: (1) educational workshops and training on CARE Act related topics at the annual U.S. Conference on AIDS; (2) regional trainings to improve the quality and availability of treatment information to communities of color; (3) capacity building in the areas of resource development, funding, and procurement for AIDS Service Organizations and the National AIDS Treatment Advocates Forum; and (4) attention to issues facing women of color, including convening the Women of Color Summit, which aims to build a national agenda to improve access to treatment and care for women of color living with HIV/AIDS.

National Pediatric and Family HIV Resource Center

University of Medicine and Dentistry of New Jersey
30 Bergen Street - ADMC #4
Newark, NJ 07103
Phone: (973) 972-0410 or (800) 362-0071 Fax: (973) 972-0399
<http://www.pedhiv aids.org/>

The National Pediatric and Family HIV Resource Center (NPHRC) offers a range of services to healthcare professionals caring for children, youth, women, and families affected by HIV infection. NPHRC provides consultation, technical assistance, and training and produces a variety of professional curricula and family educational materials.

NPHRC's cooperative agreement with HAB provides technical assistance to Ryan White Title IV projects and support to HAB to facilitate access to research opportunities for prevention or treatment of HIV in women, children, and youth. NPHRC supports access to state-of-the-art treatment, including disseminating strategies to improve medication adherence for children and families and updating antiretroviral treatment in children with HIV infection through support of a national working group and development of provider training materials. Activities also highlight unique issues facing populations such as the special needs of families living with HIV who have uninfected children and of adolescents with HIV dealing with complex medication regimens.



Selected Accomplishments

- **National Survey of CBOs and Policy Report: Impact of Changes in HIV Epidemic on PLWH Services.** CBOs asked to assess how changes in the epidemic have impacted such areas as current HIV treatments and adherence issues, client populations, and shifts in health care financing. Report to be developed in 2000. AIDS Action Foundation
- **CARE Act State Profiles.** Individual state profiles document the impact of the CARE Act funds in each state, presenting data for FY 96-98. Information for each state includes: location of CARE Act grantees, clients served, grantee accomplishments, and the characteristics of the HIV epidemic in the state (including information on co-morbidities and other funding sources such as Medicaid, the largest payer of HIV/AIDS services in the nation). NASTAD
- **Monographs on Care Issues.** Topics include: Assessing Unmet Needs; Primary Care in Rural Communities; Outcomes Data Collection and Evaluation; Linkages Among Prevention, Early Intervention, Treatment, and Essential HIV Services; Statewide Coordinated Statement of Need (SCSN); and Quality of Care. NASTAD
- **State Collaborations Among HIV, Mental Health, and Substance Abuse Programs.** Report summarizes finding from a 1999 survey of state AIDS directors on state HIV service activities with state mental health and substance abuse programs. NASTAD
- **Adherence Model Practices Manual.** In developing this document, slated for publication in Summer 2000, site visits to CBOs were conducted to gather information about innovative treatment adherence programs, particularly those targeting special populations. AIDS Action Foundation
- **White House Youth Report.** Comprehensive update of White House youth report prepared with HRSA and the White House Office of National AIDS Policy. Includes a review of progress since the first report and future directions. APC/AIDS Alliance
- **Policy/Program Notices to CBOs.** HIV-related health care policy and program information and alerts disseminated to community-based service providers and CARE Act grantees. AIDS Action Foundation
- **Your Passport to Managed Care.** A pocket-sized resource designed to help people living with HIV (PLWH) navigate managed care. The Passport explains how managed care works, answers commonly asked questions, and can assist PLWH in selecting a health plan and primary care provider. It also includes a diary for recording information about health care received. Available in English and Spanish. NAPWA
- **Client Satisfaction Survey.** Data gathered to determine client level satisfaction with services delivered by Ryan White CARE Act grantees. NAPWA
- **Annual Health Care Access Guide.** A guide for consumers listing health providers by city and state across the U.S. NAPWA
- **Annual Youth Conference.** Builds the skills of young AIDS activists; trains youth peer educators and those who work in support of young people. NAPWA



- **Staying Alive Conference.** A conference to help PLWH develop skills and confidence to be advocates for themselves and others with HIV/AIDS. NAPWA
- **Helping Communities Build Leadership.** Regional meetings across the country to enhance the abilities of communities to respond to the HIV epidemic. NAPWA
- **Medicaid Managed Care and Title IV Programs Guide.** Best practices document that will explore Medicaid managed care and programs serving women, children, and youth living with HIV/AIDS. APC/AIDS Alliance
- **HIV Testing Day.** A national campaign that educates the public about HIV counseling and testing and encourages people at high risk for HIV infection to learn their HIV serostatus by participating in voluntary anonymous and confidential HIV testing and counseling programs. NAPWA
- **"Antiretroviral Therapy and Medical Management of Pediatric HIV Infection."** Published in *MMWR*, 47, 1998 and *Pediatrics*, 102 (Suppl.), 1998. NPHRC
- ***What Women Need to Know: The HIV Treatment Guidelines for Pregnant Women and Asking Questions and Getting Answers: Choosing the Best Treatment for Your Child with HIV Infection.*** Family/consumer educational materials produced in English and Spanish. NPHRC.
- ***Women's Initiative for HIV Care and Reduction of Perinatal HIV Transmission (WIN): Program Findings.*** Prepared with HRSA staff. NPHRC
- **Working Group on Models of Services for Women with HIV Infection and Their Uninfected Children (Newark-1999).** Panel comments on program and planning recommendations for providing services to women with HIV and their families. NPHRC
- **Pediatric Adherence "Pocket Guide" and Training Materials on Supporting Adherence.** Resources for providers to support adherence, developed from a survey identifying difficulties faced by providers around adherence. NPHRC
- **Audioconference: "Mothering and HIV: Providing Services for Women with HIV Infection and Their Children."** Features a panel of researchers, clinicians and consumer advocates and reaching over 60 sites and 250 participants. NPHRC
- **Web Resources: Pediatric HIV/AIDS Care.** Offering access to materials on research and care through the NPHRC web site www.pedhivaid.org, including the full listing of projects funded through Title IV of the Ryan White CARE Act and research opportunities. NPHRC
- **Slide Set and Curriculum on "Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection."** Prepared for dissemination to AIDS Education & Training Centers and other educators. NPHRC
- **Technical Assistance Conference Call for Title IV Grantees.** Covering "Family-Centered Case Management," call was convened with new Title IV grantees. NPHRC



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act

- **Consumer Training on Participation in Grant Review Committees.** Training session and materials development for 15 consumers to facilitate their participation on HAB Objective Review Committees. Convened jointly with HAB. NPHRC
- **HHS Secretary's List of Priority Research.** On-going support for maintaining, updating, disseminating, and providing technical assistance regarding the HHS Secretary's list of priority research for Title IV grantees. NPHRC
- **Workshops on CARE Topics.** Multiple HIV/AIDS care sessions have been held at annual U.S. Conference on AIDS meetings, the nation's largest HIV/AIDS conference. NMAC
- **Treatment Information Regional Trainings.** Sessions at the annual National AIDS Treatment Advocates Forum and regional *HIV Treatment Update* assist communities of color gain access to the latest treatment information. NMAC
- **Capacity Building Workshops: Resource Development and Fiscal Management.** Training sessions for this three-city pilot project were designed for HIV/AIDS community based organizations in communities of color. In 2000, a continuation of the 1998-99 three-city pilot project will target 15 cities/regions to train HIV/AIDS community based organizations in communities of color to gain the capacity to manage federal government contracts. Proposed sites include: Atlanta, Baltimore, Chicago, Dallas or Houston, Detroit, Los Angeles, Miami, Mississippi or Alabama, New York City, Newark, Oakland, Philadelphia, Puerto Rico, St. Louis, and South Carolina. NMAC
- **Workshops: Applying for CARE Act Title III Funds.** Assistance provided in 1999 through 11 pre-application workshops providing TA to agencies applying for Title III Planning Grant Initiative funds. Upcoming workshops planned for March 2000. Toll free helpline and e-mail TA also provided. NMAC
- **Women of Color Summit.** A national forum designed to build a national agenda to improve access to treatment and care for women of color living with HIV/AIDS. NMAC
- **Computer Access/Training.** The Equal Access Initiative enhances access to on-line HIV/AIDS resources to HIV/AIDS organizations serving communities of color through: (1) a Computer Grants Program targeting smaller organizations in geographically diverse areas; (2) Internet Based training on fiscal and contract management; (3) Internet Based Treatment Education Programs; and (4) Internet Training through NMAC training sessions at national and regional levels. Ongoing TA to be provided to 105 agencies receiving computer grants. NMAC
- **On-Line Presentations.** Meet the Expert Sessions will be cast via the Internet on such issues as Fiscal Management, Planning Council, and Grant Writing. NMAC
- **Data and Evaluation Work Group.** Policy input provided to HRSA on long-term data and evaluation issues. Representatives from NASTAD, the Council of State and Territorial Epidemiologists (CSTE), HRSA and CDC reviewed the CARE Act Cross-Title Data Collection and provided input to HAB on proposed evaluation research topics for HAB's One Percent Evaluation Project. NASTAD



- **Medicaid/Medicare Dual Eligibility Forum and Report.** At a December 1999 meeting (and a follow-up report), policy makers, federal staff, service providers and consumers discussed issues facing PLWH who are dually eligible for Medicaid and Medicare. AIDS Action Foundation
- **Positive Input.** Community Planning and Ryan White Planning Process, a layman's guide to be produced in English and Spanish Spring of 2000. NAPWA
- **Consumer Education Center.** Consumer training, technical assistance, support and resource materials. First major training for women, youth, and families to be in conjunction with the annual APC conference, Voices 2000. APC/AIDS Alliance
- **Minority Access to HIV Care.** Program examples and practices for engaging Black and Latina women in high risk circumstances in the health care system. APC/AIDS Alliance
- **Latino Initiative: Assessment of TA Needs.** This two-day focus group of 25 Latino community-based organization leaders, to be held Spring 2000, will assess Latino agency organizational technical assistance and capacity building needs. NMAC



CARE Act Materials Available in Spanish

The following documents have been translated into Spanish. Many of the documents mentioned below (as indicated) can be found either in the *Title I Manual* or *Title II Manual* or in the first edition of the *PLWH Sourcebook*.

English version: ***A Compilation of the Ryan White CARE Act of 1990, as amended by the Ryan White CARE Act Amendments of 1996*** (pages 1-22) including ***Ryan White CARE Act Legislation Section 2671: Grants for Coordinated Services and Access to Research for Women, Infants, Children and Youth*** (pages 30-32). Prepared by the Division of Service Systems, HRSA, May 1996.

Spanish Version: ***Recopilación de la Ley CARE Ryan White de 1990, Modificada por las Enmiendas de 1996*** (páginas 1-22). ***Subvenciones destinadas a servicios coordinados y acceso a la investigación de mujeres, recién nacidos, niños y jóvenes*** (páginas 30-32). Preparado por: La División de Sistemas de Servicios (DSS), HRSA (17/5/96).

English version: ***List and Description of HIV Service Categories***

Spanish version: ***Glosario de Categorías de Servicios Para Infectados Con VIH***

English version: ***English - Spanish Glossary of HIV/AIDS Related Terms Found in the Following Document: Comprehensive Planning and Annual Administrative Report***

Spanish version: ***Español - Inglés Glosario de Términos relacionados con el VIH/SIDA encontrados en los siguientes documentos: Planificación Global y el Informe Anual Administrativo***

English version: ***PLWH Sourcebook: Lessons from the First Five Years***

Spanish version: ***Participación Activa de las Personas Infectadas con El Virus de Inmunodeficiencia Humano (PLWH) en los Programas de la Ley CARE Ryan White: Experiencias de los cinco primeros años***



English version: *Annual Administrative Report (AAR) The Ryan White CARE Act Title I Manual*

Spanish version: *El Informe Anual Administrativo (IAA): (AAR por sus siglas en ingles) Manual de Título I de la Ley Global de Recursos de Emergencia para el SIDA Ryan White (Ley CARE, Por Sus Siglas En Inglés)*

English version: *Ryan White CARE Act Policies from the Title I Manual*

Spanish version: *Políticas de DSS Manual del Título I de la Ley CARE Ryan White*

English version: *DSS Policy on Contracting with For-Profit Entities*

Spanish version: *Política de DSS concerniente a Contratos con Organizaciones con Fines de Lucro.*

English version: *DSS Processes for Policy Development*

Spanish version: *Proceso de BHRD/DSS para el Desarrollo de Políticas*

English version: *DSS Policy on PLWH Participation on the Title I Planning Councils*

Spanish version: *Política de DSS concerniente a la Participación de Personas Infectadas con VIH en los Consejos de Planificación*

English version: *DSS Guidelines for Reimbursement of People on the Ryan White Title I Planning Council and/or Title II Consortium*

Spanish version: *Política de la DSS para la Compensación de las Personas Involucradas en Consejos de Planificación del Título I y Consorcios del Título II de la Ley CARE Ryan White*



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act

English version: *DSS Policy on Eligible Individuals and Services for Individuals Not Infected with HIV*

Spanish version: *Política 97-01 de la DSS: Individuos Elegibles y Servicios Elegibles para Individuos no Infectados con VIH*

English version: *Allowable Uses of Funds for Discretely Defined Categories of Services*

Spanish version: *Política 97-02 de la DSS: Usos Permitidos de los Fondos para las Categorías de Servicios Discretamente Definidas*

English version: *Small EMA Profiles*

Spanish version: *Perfiles de (pequeña) EMA*



Selected Reports and Periodicals from Non-HAB Sources

In addition to the HAB materials, many studies, reports, manuals, and periodicals related to PLWH involvement are prepared by Title I and Title II grantees and planning bodies, PLWH groups, and other nonprofit organizations operating at the national, regional, and local levels. A small sample of these materials is summarized below, along with information on how to obtain copies.

Consumer Advisory Board System Information. HIV/AIDS Bureau, Massachusetts Department of Public Health (31 pages).

- **Focus:** Materials designed for members of local or state agency or consumer advisory boards, developed by the HIV/AIDS Bureau Consumer Advisory Board System of the Massachusetts Department of Public Health. Includes sample guidelines for Massachusetts Consumer Advisory Boards.
- **Content:** Includes background information about the program, its mission statement, a discussion of consumer involvement in Massachusetts, an organizational chart, and other information needed by consumer board members; specifies roles, expectations, responsibilities, and standards of behavior; rules of conduct for boards; and information on evaluating programs. Also includes sample organizational documents such as a worksheet for developing a meeting agenda, an actual meeting agenda, minutes, and participant evaluation; also provides sample selection process materials. Updated guide includes additional attachments such as sample bylaws for planning bodies.
- **Availability:** Available free from the Director, Consumer Office, Massachusetts Department of Public Health, HIV/AIDS Bureau, 250 Washington Street, Third Floor, Boston, MA 02108-4619, telephone (617) 624-5352, fax (617) 624-5399.
- **From the same source:** *Positive Voices*, a newsletter for consumer boards, available quarterly from the HIV/AIDS Bureau. It will provide consumer perspectives on various aspects of consumer board involvement, with specific emphasis on the CARE Act and a major focus on Title II consortia.

Critical Path AIDS Project. Newsletter of the Critical Path AIDS Project, affiliated with the AIDS Information Network of Philadelphia. Published quarterly (about 100 pages).

- **Focus:** Designed as a comprehensive information resource for the PLWH, medical, and service-provider community. Extensive information. Circulation exceeds 10,000, primarily PLWH.
- **Content:** Features in-depth reports on experimental AIDS treatments (both conventional and complementary). Provides updates on clinical trials, standards of medical care, personal reports on international meetings, other HIV/AIDS topics, plus extensive references, from lists of support groups to how to access AIDS information on the Internet. Noncommercial reproduction encouraged, with acknowledgment and source attribution.
- **Availability:** Subscription cost: \$50 per year; \$40 for PLWH; \$15 for low-income PLWH; free to grassroots organizations, incarcerated, or others who cannot afford to pay. Send subscription request to Critical Path AIDS Project, 2062 Lombard Street, Philadelphia, PA 19146, telephone (215) 545-2212, fax (215) 735-2762, e-mail kiyoshi@critpath.org. Also available through Critical Path's Internet Web Page: <http://www.critpath.org> or Bulletin Board: (215) 463-7160. For technical support, contact rich@critpath.org.



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act

HIV!Alive, *News, Resources, and Personal Sharing for PLHIVs*. Newsletter of the HIV Community Coalition (HCC) of the Washington Metropolitan Area. Published bi-monthly (16-20 pages).

- **Focus:** Tabloid-style newsletter providing a wide variety of information of interest to the PLWH and HIV/AIDS community.
- **Content:** Provides information on programs and services in the Washington, D.C. metropolitan area, such as changes in AIDS Drug Assistance Program (ADAP) enrollment, a table of drugs available in each of the local jurisdictions (D.C., Maryland, and Virginia), and ADAP eligibility rules by jurisdiction; a Community News page; and a list of funded CARE Act providers in the metropolitan area. Also includes national information such as legislative updates and information on HIV/AIDS care issues, plus personal stories and poetry from PLWH. It is now available in Spanish as well as English.
- **Availability:** Free subscriptions to members of the HIV Community Coalition, \$15 to non-members; waivers are available in case of hardship. Send subscription request to HIV Community Coalition, 813 L Street, S.E., Washington, D.C. 20003; telephone (202) 543-6777, fax (202) 543-7845.



Other Resources

Federal Resources - Select Listing

National HIV/AIDS Resources

The following lists contain national HIV/AIDS care technical assistance resources that are available to Title III grantees.

HRSA HIV/AIDS Bureau Technical Assistance

For information about how to access HRSA/HAB TA, see information in Section IV of this Manual and contact your HRSA/HAB project officer.

HIV/AIDS Treatment Information Service (ATIS)

ATIS—co-sponsored by HRSA and other federal agencies—provides information about federally approved treatment guidelines for HIV and AIDS through its hotline operators and website.

Phone: (800) 448-0440

Fax: (301) 519-6616

Hours: Mon-Fri, 9 a.m. - 7 p.m.

<http://www.hivatis.org/>

HRSA AIDS Education and Training Centers (AETC)

HRSA's AETC Program is a network of 15 regional centers (with more than 76 local performance sites) that conduct targeted, multidisciplinary HIV education and training programs for health care providers. The mission of these centers is to increase the number of health care providers who are effectively educated and motivated to counsel, diagnose, treat and manage individuals with HIV infection and to assist in the prevention of high risk behaviors which may lead to infection. A listing of AETCs is included in the Contacts Section of the Title III Manual.

Phone: (301) 443-6364

Fax: (301) 443-9887

<http://www.hrsa.gov/hab>

HRSA/AETC National HIV Telephone Consultation Service (Warmline)

For health care providers only. The HRSA/AETC Warmline offers physicians and other health care providers timely HIV clinical information and case consultation across the broad range of clinical HIV/AIDS problems.

Phone: (800) 933-3413

Hours: Mon-Fri 7:30 a.m. - 5 p.m. Pacific and by voice mail 24 hours

<http://itsa.ucsf.edu/warmline/warmline.html/>



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act

HRSA/CDC National Clinicians' Post-Exposure Prophylaxis Hotline (PEPLine)

The HRSA/CDC PEPLine provides free phone consultations for clinicians treating occupational exposure to HIV and other bloodborne pathogens.

Phone: (888) HIV-4911

Hours: 24 hours a day/7 days a week

<http://itsa.ucsf.edu/warmline/pepline.html/>

AIDS Clinical Trials Information Service (ACTIS)

ACTIS provides access to information on federally and privately funded clinical trials.

Phone: (800) 874-2572

Hours: Mon-Fri, 9 a.m. - 7 p.m.

<http://www.actis.org/>

CDC National Prevention Information Network

CDC's National Prevention Information Network, formerly known as the National AIDS Clearinghouse, provides reference, referral and distribution services on HIV/AIDS, STDs, and TB.

Phone: (800) 458-5231

Fax: (301) 738-6616

Hours: Mon-Fri, 9 a.m. - 6 p.m.

<http://www.cdcnpin.org/>

CDC National AIDS Hotline

The National AIDS Hotline provides phone information and referrals on HIV/AIDS, including questions about counseling/testing, informational materials, and other resources.

English Service	Phone: (800) 342-AIDS	7 days/week, 24 hours/day
-----------------	-----------------------	---------------------------

Spanish Service	Phone: (800) 344-7432	7 days/week, 8 a.m. - 2 a.m.
-----------------	-----------------------	------------------------------

TTY Service for the Deaf	Phone: (800) 243-7889	Mon-Fri, 10 a.m. - 10 p.m.
--------------------------	-----------------------	----------------------------

Health Care Financing Administration

Administers the Medicaid and Medicare Programs. In partnership with State Medicaid Agencies, HCFA's Medicaid Program pays for 53 percent of the care provided to persons living with AIDS and for the care of 90 percent of the children living with AIDS in the United States.

Phone: (410) 786-1357

Fax: (410) 786-9004

<http://www.hcfa.gov/>

National Institute on Drug Abuse

Supports research to improve prevention, research and policy on drug abuse and addiction.

Phone: (301) 443-6046

Fax: (301) 443-4100

<http://www.nida.nih.gov/>

People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act



National Institutes of Health Office of AIDS Research

Directs the scientific, budgetary, legislative and policy elements of the NIH AIDS research program. OAR also plans, coordinates, evaluates and funds all NIH AIDS research.

Phone: (301) 496-0357

Fax: (301) 496-2119

<http://www.nih.gov/od/oar/index.htm>

Office of Minority Health, Office of the Secretary, U.S. Dept. of Health and Human Services

Advocates and monitors all policies and programs geared to improving the health of racial/ethnic minority populations and to eliminating the health disparities that exist between minority and non-minority populations.

Phone: (301) 443-9923

Fax: (301) 443-8280

<http://www.omhrc.gov/>

Substance Abuse and Mental Health Services Administration Office on AIDS

Coordinates and monitors SAMHSA activities that address the critical public health problems posed by HIV disease among substance abusers and persons with mental illnesses.

Phone: (301) 443-5305

Fax: (301) 443-3817

<http://www.samhsa.gov/>

United States Department of Housing and Urban Development Housing Opportunities for Persons with AIDS (HOPWA)

Provides housing assistance and supportive services for low-income people with HIV/AIDS and their families.

Phone: (202) 708-1934

Fax: (202) 708-1744

<http://www.hud.gov/cpd/hopwahom.html>

National HIV/AIDS Organizations

AIDS National Interfaith Network

1010 Maryland Avenue, NE, Suite 108

Washington, DC 20002

Phone: (202) 543-1202

Fax: (202) 543-2256

<http://www.anin.org/>



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act

American Association for World Health

1825 K Street, N.W., Suite 1208
Washington, DC 20006
Phone: (202) 466-5883
Fax: (202) 466-5896
<http://www.aawhworldhealth.org/>

American Foundation for AIDS Research

120 Wall Street, 13th Floor
New York, NY 10005
Phone: (212) 806-1600
Fax: (212) 806-1601
<http://www.amfar.org/>

American Nurses Association

600 Maryland Avenue, S.W., Suite 100 West
Washington, DC 20024-2571
Phone: (202) 651-7000
Fax: (202) 651-7001
1-800/274-4ANA
<http://www.nursingworld.org/>

The National AIDS Fund

1400 I Street, N.W., Suite 1220
Washington, DC 20009
Phone: (202) 408-4848
Fax: (202) 408-1818
<http://www.aidsfund.org/>

National Hemophilia Foundation

116 West 32nd Street, 11th Floor
New York, NY 10001
Phone: (212) 328-3700
Fax: (212) 328-3777
<http://www.hemophilia.org/>

National Lesbian and Gay Health Association

1407 S Street, N.W.
Washington, DC 20007
Phone: (202) 939-7880
<http://www.nlgha.org/>

People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act



National Native American AIDS Prevention Center

134 Linden Street
Oakland, CA 94607
Phone: (510) 444-2051
Fax: (510) 444-1593
<http://www.nnaapc.org>

Title II Community AIDS National Network (T II CANN)

1775 T Street, NW
Washington, DC 20009
Phone: (202) 588-1775
Fax: (202) 588-8868
<http://www.t2cann.org/>

HIV/AIDS Web Resources - Select Listing

The following websites are just a sample of the wide array of Internet resources. Most of these sites include links and lists of other websites that represent valuable resources.

AEGIS (AIDS Education Global Information System)

<http://www.aegis.com/>

Maintains a comprehensive database, library, and search engine for information on HIV/AIDS, including information on treatment, prevention, living with HIV, science, law, government and policy, and extensive news information resources, including medical journals, community newsletters, and popular press.

AIDS Treatment Data Network

<http://www.aidsinfonyc.org/network/>

Provides treatment-related information, including guidelines, fact sheets, information on alternative treatments, a glossary of drugs, and an information clearinghouse on medications available for HIV and AIDS through Medicaid, AIDS Drug Assistance Programs (ADAPs), and national pharmaceutical industry patient assistance/expanded access programs.

The Body

<http://www.thebody.com/>

Includes information on AIDS basics and prevention, treatment, conferences, quality of life, and government and policy.

Critical Path AIDS Project

<http://www.critpath.org/>

Provides treatment and prevention information in wide-ranging levels of detail—for researchers, service providers, treatment activists, and for people living with HIV/AIDS.



People Living with HIV/AIDS (PLWH) Sourcebook

Describing the Involvement of PLWH in the Ryan White *C.A.R.E.* Act

HIVInSite (University of California, San Francisco)

<http://hivinsite.ucsf.edu/>

Contains information on medical management of HIV infection, prevention and education, social and policy HIV/AIDS issues, statistics and epidemiology, and a listing of Spanish language resources and international reports.

JAMA (Journal of the American Medical Association) HIV/AIDS Information Center

<http://www.ama-assn.org/special/hiv/>

Includes news briefings, collections of the latest medical literature on HIV/AIDS, treatment information, resources for patients and professionals, and information on prevention and policy.

Johns Hopkins AIDS Service

<http://www.hopkins-AIDS.edu/>

Provides information on medical education, managed care, epidemiology, prevention and treatment, and an interactive, question-and-answer forum designed for clinicians to utilize the expertise of HIV specialists at the Johns Hopkins AIDS Service.

Medscape HIV/AIDS (formerly known as Clinical Care Options for HIV)

<http://hiv.medscape.com/>

Includes treatment updates, clinical management, practice guidelines, conference summaries and schedules, clinical summaries and highlights in HIV/AIDS from current journals, patient resources, and information on managed care.

Contact Information for Models of PLWH Involvement

Effective models of PLWH involvement are described in Section 5. Contact lists for these programs can be found in Section 5, pp. 16-17. Or you can contact your HAB project officer for further information: see HAB contact information in Section 3, pp.7-8 and at the beginning of Section 9.